



HOUSING FOR ADULTS WITH INTELLECTUAL DISABILITIES

INTRODUCTION

This study examined the housing issues that adults with intellectual disabilities and their families are facing. Conducted between December 2004 and February 2006, it addressed:

1. the availability of housing and associated support services;
2. best practices;
3. transitions between housing situations;
4. the role of parents of adults;
5. risks that face persons with intellectual disabilities as they transition out of the family home or the juvenile system; and
6. gaps in the availability of housing, both existing and anticipated.

The research focused on three cities: Victoria, Ottawa and Halifax, with some input from stakeholders in other provinces. While not national in scope, nor exhaustive in its methods, it provides an overview of the housing and support issues facing adults with intellectual disabilities.

In 2001, there were 120,140 Canadians over the age of 15 with developmental disabilities¹. Family members are the only, or the main source of support for almost 80 per cent of adults with intellectual disabilities. Fifty per cent of family members providing support indicate they are not getting the back-up assistance and in-home support they need from their communities.

Approximately 12 per cent of individuals with developmental disabilities are aged 65 and over, and population projections indicate that, because these people are living longer than they used to, the population of developmentally disabled people who are 55 years of age or older will double within the next 25 years. These individuals and the families who support them are likely to encounter a number of life transition issues, as both the parents and their adult children age. Many individuals and families continue to be presented with options that do not support lifestyles of choice but instead demand that people with developmental disabilities stay indefinitely in the family home, or move into group home programs or other considerably more institutional environments.

METHODOLOGY

The study pursued three lines of enquiry

- **A literature review:** The literature review focused on North American sources, primarily those available on the web. An Internet search using key words related to housing for people with intellectual disabilities generated many publications, the majority of which were American. Other materials were generated through discussions with individuals working in the field of developmental disability with responsibility for supporting people with their residential needs, and engaged in creative developments in this field.
- **Interviews:** Thirty-nine telephone interviews were conducted with a range of government respondents, service providers, academics, and with representatives of relevant associations. Interviewers worked from a 17-question interview guide that included both open and closed questions.
- **Focus groups:** Nine focus groups comprising 83 participants were conducted—three each with people with intellectual disabilities (consumers), the families of consumers, and service providers in Victoria, Ottawa, and Halifax.

¹ Cossette, L. and Duclos, E. (2002). *A Profile of Disability in Canada 2001* (No. 89-577-XIE). Ottawa, Statistics Canada: Housing, Family and Social Statistics Division.

FINDINGS

Availability of Appropriate Housing and Support Services

Overwhelmingly, the participants in the study reported a significant gap between the housing needed and the housing available. They also indicated that providing the physical facilities is not the most difficult problem to address—of more concern is the availability of adequate and appropriate support services, including well-trained staff. These two factors combine to produce a reactive rather than a pro-active system—a family in crisis can almost always find a bed when the need is urgent, but the bed may be inappropriate, and planning for a smooth transition from a family home to a more independent living environment is seldom addressed.

As a result, and too often, adults with intellectual disabilities are housed in facilities that are not necessarily best suited to their needs.

A Desire to Live Independently

Adults, including those with intellectual disabilities, usually want to live independently. They want to make their own decisions on whom to live with, where to live, and what to do with their time. People with intellectual disabilities face extra challenges in working towards that goal, however, such as

- limited financial resources, usually in the form of government pensions which impose restrictions on their other earnings or on living conditions
- limited support services that could assist them in planning for and effecting the transition to independent living and subsequently provide the specific support services they would need to live independently
- a system that is geared to accommodating them within existing housing, rather than creating housing situations geared to their needs
- families and support organizations that fear for their safety or question their ability to live on their own

Financial Issues

A repeated theme in interviews and focus groups was the lack of funding from governments, coupled with limited family financial resources. The preferred housing option—private accommodations with support services as required—is primarily available to those families with the resources to purchase a home or apartment.

A range of financial considerations and funding policies are considered to have a negative impact on a family's ability to provide for their adult children with intellectual disabilities, such as

- restrictive or claw-back provisions in pension programs that keep an individual in poverty
- estate planning regulations that make it difficult to provide for children without losses from taxation
- mortgage rates that do not differentiate between regular mortgages, and those required to assist families in adapting their homes to keep their adult children in the family home
- financial institutions whose lending criteria do not recognize disability pensions as assurance for mortgage payments

Impact of Municipal By-Laws

A range of municipal policies, or the interpretation and application of municipal policies, can have an impact on the availability of housing for adults with intellectual disabilities. For example, application of the building and safety requirements intended for institutional facilities to group homes can render them prohibitively expensive.

Best Practices

Flexibility and choice: Many housing models emerged as desirable in different circumstances. The underlying principle that unifies them is consistent, however: the need for flexibility and choice. There is such variation in the abilities, needs and desires of people with intellectual disabilities and their families, that there must be a corresponding range of housing and support options.

De-linked funding: There was also a desire to separate physical housing from service supports, so that funding for services for an individual would not be tied to his or her residence. Currently, if a resident is unhappy with the quality or level of services provided, she or he often must change residences in order to change services.

The person-centred approach: This approach is one in which the person with an intellectual disability or his or her advocate is directly involved in planning and choosing the housing and support services that will best meet his or her needs. Typically, in a person-centred approach, funding is portable, tied to the individual rather than to an agency or a facility.

Favoured Housing Models

A number of options or models were cited as best practices that embody the over-arching principle of flexibility and choice.

Independent living model: An independent living model is one in which the person with an intellectual disability lives independently, often sharing a house or apartment with other consumers and/or with service providers. Service providers may also be close by (for example in a neighbouring apartment) instead of sharing living quarters.

Co-ops and co-op-like arrangements: In co-op housing, a group gets together, builds their own multi-unit building, and gives up some private space for community space. Residents are people who want not just housing, but also community support.

Home ownership/adaptation of family homes: This option, while cited by many study participants as a best practice, is one that is rarely available to most people with intellectual disabilities.

L'Arche model: L'Arche was the only group home that was identified as a best practice. L'Arche homes exist in a number of provinces. All are faith-based, geared to aging-in-place, and feature employees who function more like family members than staff.

As part of a seniors' complex: A number of study participants felt that adults with intellectual disabilities need the same types of supports typically provided in seniors' residences, and saw merit in combining facilities for seniors and adults with intellectual disabilities.

CONCLUSION

The research found that there is a significant unmet need for suitable housing for adults with intellectual disabilities, resulting from a lack of funding for physical facilities and supports. As well, the current system which provides housing for adults outside their family home is geared to meeting the needs of the system rather than those of the individuals it is meant to serve. Too often, individuals are housed where space is available, rather than in residences suited to their specific needs.

Making the transition from a family home to independent living can be difficult for any adult, but more so for adults with intellectual disabilities, because of their more limited ability to cope with the challenges of adapting to new situations and taking on new responsibilities. The shortage of support services can therefore be an impediment to a successful transition.

Family members, especially aging parents, want to participate in planning for the transition to other forms of housing and to have input to the decisions that affect their family members. While most service providers share that concern, their resources are often such that a desire for a pro-active and responsive approach is not translated into reality.

While many housing models emerged as desirable in different circumstances, they have a common focus on flexibility and choice, reflecting the variation in the abilities, needs and desires of people with intellectual disabilities and their families. Finally, study participants advocate a person-centred approach, in which people with intellectual disabilities or their advocates are directly involved in planning and choosing housing and support services, and in which funding is tied to the individual rather than to an agency or facility.

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Housing Research at CMHC

Under Part IX of the *National Housing Act*, the Government of Canada provides funds to CMHC to conduct research into the social, economic and technical aspects of housing and related fields, and to undertake the publishing and distribution of the results of this research.

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